

Quality of Breast Cancer Care: Perception Versus Practice

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ABSTRACT

Purpose

Because insurers use performance and quality metrics to inform reimbursement, identifying remediable causes of poor-quality cancer care is imperative. We undertook this descriptive cohort study to assess key predictors of women's perceived quality of their breast cancer care and actual guideline-concordant quality of care received.

Patients and Methods

We surveyed inner-city women with newly diagnosed and surgically treated early-stage breast cancer requiring adjuvant treatment who were enrolled onto a randomized controlled trial (RCT) of patient assistance to reduce disparities in care. We assessed women's perceived quality of care and perceived quality of the process of getting care, such as getting referrals, test results, and treatments; we abstracted records to determine the actual quality of care.

Results

Of the 374 new patients with early-stage breast cancer enrolled onto the RCT, only a slight majority of women (55%) perceived their quality of care as excellent; 88% actually received good-quality, guideline-concordant care. Excellent perceived quality ($P < .001$) was significantly associated with patients' perception of the quality of the process of getting care (adjusted relative risk [RR], 1.78; 95% CI, 1.65 to 1.87). Also associated with perceived quality—and mediated by race—were trust in one's physician (adjusted RR, 1.43; 95% CI, 1.16 to 1.64) and perceived racism, which affected black women more than women of other races/ethnicities (black race-adjusted RR for perceived racism, 0.33 [95% CI, 0.10 to 0.87]; black race-adjusted RR for trust, 1.61 [95% CI, 0.97 to 1.90]; $c = 0.82$ for the model; $P < .001$). Actual quality of care provided did not affect perceived quality of care received.

Conclusion

Patients' perceived quality of care differs from their receipt of high-quality care. Mutable targets to improve perceived quality of care include the processes of getting care and trusting their physician.

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INTRODUCTION

Increasingly, physician and hospital payments are being tied to performance.¹⁻³ Quality measures of care processes, as well as patient satisfaction, are informing levels of reimbursement for increasing proportions of practices.⁴ The Patient Protection and Affordable Care Act of 2010 includes Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) measures in addition to process of care measures for calculating value-based incentive payments, which will start in October 2012.⁵ The HCAHPS assesses patients' hospital experiences, including communication with nurses and physicians, responsiveness of staff, pain management, and overall rating of the hospital, among other things. The 2010 Medicare Physician Quality Reporting Initiative⁶ includes five quality measures for breast cancer care of which

20% are devoted to patient-reported experience. The movement toward improved quality is inexorably linked with the movement to eliminate racial disparities in quality of care^{7,8} and strengthens the need to identify causes of disparate quality ratings. As pay-for-performance measures gain momentum with both public and private insurers,^{9,10} patient's perception of their quality of care becomes more important. We undertook this study to identify potentially remediable areas for improving women's experiences, perceptions, and ratings of the quality of their cancer care and their relationship to typical quality measures of care processes.

PATIENTS AND METHODS

This descriptive study was part of an institutional review board–approved randomized controlled trial at eight hospitals in New York City to test the effectiveness of patient

assistance in reducing disparities in care. Eligible women with newly diagnosed early-stage breast cancer were identified shortly after their definitive surgical treatment. None of the patients had a previous history of cancer and none had prior neoadjuvant radiation or chemotherapy. Hospitals included four tertiary academic referral centers and four municipal hospitals; among the 40 surgeons, 16 were in faculty practice, 11 were in solo or group private practice, and 13 were in municipal hospital clinic practices.

Patients were surveyed via telephone at baseline to assess their experiences with cancer care and their knowledge, attitudes, and beliefs about breast cancer and its treatment; they were resurveyed at 6 months to assess both their perceived quality of care and their perceived quality of the process of getting care. The actual guideline-concordant quality of care they experienced was based on inpatient and outpatient medical record abstraction and was defined as receipt of radiotherapy for women undergoing breast-conserving surgery, receipt of hormonal therapy for women with estrogen receptor-positive tumors ≥ 1 cm, and chemotherapy for women with estrogen receptor-negative tumors ≥ 1 cm.¹¹ Poor-quality care was defined as episodes in which needed adjuvant therapy was not received. Women were asked to identify the physician who most influenced their decisions about cancer treatments and how well their physician's office staff treated them—very well, somewhat well, somewhat poorly, very poorly. For the primary outcome variable, women rated their overall medical care for breast cancer as excellent, very good, good, fair, or poor. Their responses were then dichotomized into excellent quality care versus anything less than excellent quality care. Women were also asked to rate the process of getting their medical care, including getting appointments, referrals, test results, and treatments (physician care was excluded), with responses similarly varying from excellent to poor. Responses were dichotomized into excellent versus anything less than excellent. Physician communication was based on a five-item instrument calibrated to a 100-point scale (Cronbach's $\alpha = .82$).¹² Trust was based on a validated instrument and calibrated to a 100-point scale (Cronbach's $\alpha = .71$).¹³ Perceived racism was based on a four-item calibrated instrument (Cronbach's $\alpha = .81$), and medical mistrust was based on a three-item scale (Cronbach's $\alpha = .65$).¹⁴ Emotional health status was measured by the emotional component of the Short Form 12 (SF-12).¹⁵ Thirteen women did not respond to one or two scale items, which were later imputed on the basis of their responses to other questions within that domain.¹⁶ Logistic regression was used to assess the strength of association of variables significant in the bivariate analyses with excellent quality care ratings. Odds ratios were converted to adjusted relative risk.¹⁷

RESULTS

In all, 1,151 women with a new, primary early-stage breast cancer who had surgery between October 2006 and September 2009 at one of eight participating hospitals in New York City were identified from pathology; 398 were subsequently found to be ineligible for this study, and 95 could not be reached after 20 phone calls on different days and at various times of day. Of the remaining 658, 274 (42%) refused to participate in the parent randomized clinical trial; 384 (58%) of 658 women consented, and of those, 374 (97%) completed the baseline survey. There was no significant difference in age, surgery type (mastectomy v breast-conserving therapy), breast cancer stage, or hospital between women who could be reached by telephone compared with those who could not be reached. Of the 374 participants, 45% were white, 20% black, 30% Hispanic, 4% Asian, and 1% other. Nearly 80% of women had a high school education or better. About one third of women had incomes below the poverty line ($< \$15,000/\text{yr}$). The vast majority of women (94%) had some form of health insurance. Most (56%) were covered by commercial insurance; 26% were uninsured or covered by Medicaid (Table 1).

Of the 374 women, a slight majority (55%) rated their care as excellent. Women were more likely to rate the quality of their care as

Table 1. Characteristics of Study Population (N = 374)

Characteristic	No.	%
Age, years		
Mean	57	
Range	28-89	
Race		
White	167	45
Black	75	20
Hispanic	113	30
Asian	15	4
Other	3	1
Education completed		
\geq High school	277	79
$<$ High school	74	21
Insurance (from medical record)		
Commercial	209	56
Medicaid/none	96	26
Medicare	68	18
Annual income, \$		
$< 15,000$	104	31
$\geq 15,000$	228	69

NOTE. Totals may not add up to 374 because of missing data.

excellent if they also reported the processes by which they got that care as excellent ($P < .008$), reported excellent treatment by clinical staff ($P < .001$), knew which physician to go to with questions or concerns ($P \leq .001$), and described their physician as one who communicated well about issues of treatment decision making ($P < .001$). Women who rated their care as excellent were more likely to trust their physician ($P < .001$) and less likely to mistrust the medical system ($P < .001$; Table 2). Black women were considerably less likely to report excellent quality of care compared with white and Hispanic women (39% v 60% v 62%, respectively; $P = .002$), less likely to trust their physician (93 v 96 v 97 on a 100-point scale; $P = .003$), and more likely to perceive racism in the medical delivery system (51 v 48 v 40 on a 100-point scale; $P = .007$). Perceived quality ratings were not associated with physical health, income level, education level, type of insurance, racial concordance between physician and patient, hospital at which surgery was performed, or surgeon.

Multivariate analysis found that the process of getting medical care and trust of a physician predicted excellent quality ratings. African American women and those who perceived greater racism were less likely to rate their care as excellent. Because race differentially modified levels of trust of a physician and perceived racism, interaction terms were included in the model (Table 3). Women's emotional health status and physician communication were not significantly associated and were dropped from the final model.

Women who rated the process of getting care as excellent compared with those who did not were more likely to know which physician to call if they had questions (84% v 74%; $P = .02$) and to feel that their physician's ancillary staff treated them well (95% v 82%; $P = .002$; Table 2). Despite the close relationship between women's ratings of the process of getting care and how well they were treated by ancillary staff, only 44% of women who were treated well by ancillary staff rated the process of getting care as excellent ($P = .002$). This finding suggests that there are other important components beyond staff-patient interactions that affect women's ratings of the process of getting care. The ratings of the

Table 2. Factors Associated With Quality of Care (N = 374)

Factor	Excellent Quality of Care (n = 205)			Less Than Excellent Quality of Care (n = 169)			P
	No.	%	SD	No.	%	SD	
Income, \$							N/S
< 15,000	56	31		48	32		
≥ 15,000	125	69		103	68		
Education completed							N/S
< High school	43	22		31	20		
≥ High school	151	78		126	80		
Insurance							N/S
Medicare	36	18		32	19		
Commercial	116	57		93	55		
Medicaid/none	52	25		44	26		
Treatment by medical staff							.011
Excellent	186	92		138	83		
Less than excellent	17	8		29	17		
Race							.002
African American	29	15		46	30		
White	101	51		66	43		
Hispanic	70	35		43	28		
Racial concordance with physician							N/S
Same race	93	49		70	44		
Different race	96	51		88	56		
Patient knows which physician to speak with about care							< .001
Knows	176	86		117	69		
Does not know	29	14		52	31		
Adjuvant treatment							N/S
Treated	169	87		149	90		
Not treated	26	13		17	10		
Rate of process of getting care							< .001
Excellent	124	60		28	17		
Less than excellent	81	40		141	83		
Trust in physician*	98		4.2	92		9.9	< .001
Physician communication score*	90		14.7	82		18.2	< .001
Medical mistrust*	45		21	55		21	< .001
SF-12 Mental Health	53		11.3	51		9.6	.0801
SF-12 Physical Health	51		10.3	50		1.8	N/S

Abbreviations: N/S, not significant; SD, standard deviation; SF-12, 12-item short form.

*Based on 100-point scale.

Table 3. Multivariate Model of Factors Predicting Quality of Care

Variable	Adjusted RR	95% CI	P
Black	0.55	0.17 to 1.21	.1751
Perceived racism	0.88	0.63 to 1.15	.3914
Process of getting care	1.78	1.65 to 1.87	< .001
Trust physician	1.43	1.16 to 1.64	.0026
Underuse of treatment	1.08	0.70 to 1.43	.7035
Black racism interaction*	0.33	0.10 to 0.87	.0191
Black trust interaction*	1.61	0.97 to 1.90	.0613

NOTE. $c = 0.815$; $P < .001$ for model.

Abbreviation: RR, relative risk.

*All variables with statistical significance or trend significance in relation to quality of care were entered in the stepwise model selection, which include race, treatment from staff, medical mistrust, rating process of getting care, trust in physician, and physician communication. Underuse of adjuvant treatment was entered as a control after initial model selection.

factor of race. We found that 81% of women who reported good communication with their physician versus 53% of those who did not have higher levels of trust in their physician ($P < .001$). Trust of physician was also affected by interactions with ancillary staff: 69% of women who were treated well by staff compared with 54% of those who were not, reported greater trust in their physician ($P = .05$). Women with higher levels of perceived racism had lower levels of trust ($r = .21$; $P < .001$). Black women had higher levels of perceived racism than women of other races or ethnicities (51 v 45; $P = .02$) and lower levels of physician trust (93 v 96; $P = .01$). There was no significant interaction between race and ratings for the quality of the process of getting care. Ratings of physician trust and communication were not affected by racial concordance between patient and physician.

DISCUSSION

Because insurers are moving toward pay for performance, quality measures and factors that affect patients' perceived quality of cancer care are becoming more important.^{4,18-20} Disturbingly, more than a decade after the Institute of Medicine's report titled "Ensuring Quality Cancer Care"²¹ issued recommendations for improving the quality of cancer care without delineating how, we found that nearly half the women in our study reported the quality of their breast cancer care to be less than excellent. These ratings are lower than national averages for hospital-reported quality of care²² and similar to perceptions of quality of cancer care elicited a decade ago.²³ What lessons can we learn and where do we go from here to improve the quality of cancer care? First, there is a clear disconnect between patients' perceived quality of care and the evidence-based processes of care proven to increase survival that are typically used to measure actual quality of care.^{24,25} Patients' experiences are influenced by factors other than the technical aspects of the quality of their medical care, such as responsiveness, communication, and even cleanliness of their care sites.^{26,27} Perceived quality is strongly affected by the challenges of getting care, including the idiosyncrasies of getting appointments, referrals, tests, and test results and how patients are treated by office staff. These factors, combined with a physician's ability to effectively communicate information about diagnosis and treatment and to facilitate decision making, affect women's trust of their physician and significantly affect quality ratings. Patients' prior experience with the medical care

process of getting care did differ by hospital; higher proportions of patients at municipal hospitals rated the process as excellent compared with patients at academic hospitals (52% v 38%; $P = .06$).

There was no significant relationship between women's perceived quality of care or quality of the process of getting care and actual receipt of good-quality care, as measured by receipt of adjuvant therapy. Overall, 12% of women experienced underuse of effective adjuvant therapy and did not receive adequate adjuvant treatment. Fifty-three percent of women who experienced underuse versus 60% of women who experienced appropriate treatment reported receiving excellent quality of care ($P = .366$).

Trust of physician, which affected ratings of perceived quality of care, was related to mutable factors, including communication with one's physician, interactions with ancillary staff, and the nonmutable

delivery system affects their level of trust, and their perceptions in turn affect both rates of treatment receipt²⁸ and perceived quality, thus reinforcing the need to improve not just what we do but how we do it.

Medical office staff are often the first contact patients have with the medical care delivery system—they are the “face” of a physician’s practice. Office staff control triage along with access to physicians, referrals, and test results and can be important conduits in communicating and coordinating care, thereby enabling a physician’s practice to run smoothly and efficiently while keeping patients informed and engaged in their own care. That patients’ interactions with staff strongly affect their perceived quality of care is not surprising. In fact, when popular vendors assess the quality and safety culture of a physician’s office, they consider the specifics of staff communication, follow-up, organization, management, and leadership in addition to structural elements of care.^{22,23,29} Medicare uses patients’ experiences, perceptions, and ratings of care and the technical processes of getting care to calculate reimbursement rates, demonstrating that insurers understand that good quality is defined by both care processes and care experiences.^{5,30}

Importantly, we found that perceived quality ratings did not vary significantly by individual hospital or by physician. Thus, it is unlikely that it is simply a single “bad apple” practice or practitioner contributing to the poorer ratings women report. However, both the process of getting care and patients’ sense of perceived racism did vary by hospital. Interestingly, patients treated at municipal hospitals reported higher quality of the process of getting care than those treated at academic centers. The academic hospitals in our study were significantly larger and busier, with greater volume than the municipal hospitals; it is not clear whether it is the breadth of services and the complexity of high-volume institutions or their approach to patient care and their culture that contributed to their lower ratings. Our findings may reflect the difficulties of navigating a large tertiary referral hospital, women’s self-selection to the participating hospitals, or a need for improved culture at these hospitals. We are unable to ascertain from our data whether it was single or multiple events that negatively affected women’s perceptions of the quality of their care, which makes it more difficult to identify key components of care provision that need to be addressed or sites that may need intervention to improve their quality of care.

Moving forward, the challenge for hospital cancer centers is one shared by most health care delivery systems—how to make a cultural shift in access to care, delivery of care, and approach to communication that creates safe, reliable, and patient-centered treatment experiences. Improving customer service skills, creating incentives for quickly responding to patients’ requests, ensuring a culture of teamwork and open communication, and supporting quality care and patient safety are approaches that are being tried.²² Administrators are retooling their hospital discharge planning to improve case management, communication, and the coordination of patient-centered care to avoid the financial penalties of readmissions. Their efforts may provide insights into how to smooth the complex processes of multidisciplinary outpatient care that patients with cancer require without alienating them. Despite the certainty that improving coordination, communication, and teamwork will improve patient outcomes, compelling evidence demonstrating the effectiveness of these efforts remains elusive.^{31–34}

Black race was an important factor that affected patients’ ratings of quality of care. Variable item ratings may reflect a group’s tendency

to rate responses along a different scale resulting in a measurement bias rather than reflecting actual disparate care experiences.^{35,36} We do not believe such a measurement bias explains our findings because higher proportions of black women used the “excellent” response category for other ratings. However, we found significant interactions between race, trust, and perceived racism showing that black women who had greater trust in their physician rated the quality of their care higher, and black women who had greater perceived racism rated their quality of care lower. Race was not related to the process of getting care, which suggests that race was not a factor in the actual experience of obtaining needed tests, results, and appointments; the delivery systems in this study treated women equally, regardless of race or ethnicity. Thus, something is being communicated to black women that results in their lower levels of trust and higher perceived racism. These sentiments vary among black women, which suggests that there are ways to redress this critical issue. Enhancing patient-centered communication increases partnership building^{37,38} and may improve quality of life³⁹ and emotional well-being for patients.⁴⁰ Increased listening, information giving, and involvement in decision making, along with increased consultation time on the part of the physician^{41,42} are associated with higher trust levels in patients. Such approaches can affect critical outcomes as evidenced by patients with breast cancer who report having more knowledge of their disease²⁸ and more information about treatment⁴³; they also report receiving more emotional support from their physicians, which can provide a foundation on which to build improvements in quality care.

Our study cohort consisted of an inner-city population in New York City, so our results may not be generalizable to all groups. The survey was administered in both English and Spanish, so the results may not be generalizable to groups that speak other languages. Our study sample had a large proportion of poorer and less educated women, but any effects that might have been caused by illiteracy were minimized because we used a telephone survey. Fifty-seven percent of eligible and reachable women agreed to participate in the parent clinical trial and responded to the survey. For survey research, 57% is an average response rate, and it is also a respectable percentage of patients with cancer who agreed to participate in a clinical trial.⁴⁴

In this study, women’s perceived quality of care was not associated with national metrics of good-quality breast cancer care. The processes of getting care, gaining physician trust, and patients’ perceived racism independently predicted excellent ratings for quality of care. As physicians and office staff strive to provide excellent patient-centered cancer care, they must improve the way they talk with, treat, and enable patients to help coordinate their own cancer care

AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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